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ABSTRACT

The annotated bibliography is intended to give classroom teachers and educational planners background information and resource materials on the psychosocial and health concerns of adolescents with chronic illnesses. The 26 bibliographic citations date from 1980 to 1988 and are grouped into the following categories: general medical and social aspects--books, demographic, school issues, and psychosocial and family issues. Five descriptions of training materials provide: material title, supplier, address, phone number, producer and date, keywords, and a narrative abstract. The six program descriptions include: name of the program, contact person(s), affiliation, address, phone number, keywords, and a narrative abstract. (DB)

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National Center for Youth with Disabilities

. . . a resource center to improve services for youth with disabilities.

CYDLINE Reviews:

Adolescents with Chronic Illnesses— Issues for School Personnel

September, 1989

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Society for Adolescent Medicine
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The National Center for Youth with Disabilities is a collaborative project of the Society for Adolescent Medicine and the Adolescent Health Program at the University of Minnesota. The Center is supported through a grant from the Bureau of Maternal and Child Health and Resources Development, Division of Services for Children with Special Health Needs, Department of Health and Human Services, #MCJ27361-010. The Center's mission is to raise awareness of the needs of youth with disabilities; foster coordination and collaboration among agencies, professionals, parents, and youth in planning and providing services; and provide technical assistance and consultation.

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10M12LP003

National
Center for

Youth with Disabilities

September, 1989

Dear Colleague:

The National Center for Youth with Disabilities (NCYD) is pleased to send you this bibliography on materials for educators regarding adolescents and young adults with chronic illnesses. Funded by a grant from the Bureau of Maternal and Child Health and Resources Development, Department of Health and Human Services, NCYD's mission is to raise awareness of the needs of youth with disabilities; foster coordination and collaboration among agencies, professionals, parents, and youth in planning and providing services; and provide technical assistance and consultation. In keeping with this mission, we are preparing a series of bibliographies targeted to specific groups. This bibliography, *Adolescents with Chronic Illness—Issues for School Personnel,* is intended to give classroom teachers and educational planners background information and resource materials on the psychosocial and health concerns of adolescents with chronic illnesses.

This bibliography represents a very small portion of the wide range of interdisciplinary information found in the NCYD Resource Library. For a modest fee, you can request a search on any psychosocial topic related to youth with disabilities (e.g., sexuality, independent living, self-esteem, education, etc.). Alternatively, the computerized database is directly accessible through a microcomputer and modem.

We invite you to copy this bibliography and forward it to anyone you think could benefit. In approximately one month, we will send a short evaluation form to determine how useful this bibliography was to you.

If you would like to request an individualized search of the Resource Library, or if you have further questions, please call us at 1-800-333-6293.

Sincerely,

Gayle Geber

Gayle Geber
Program Director
National Center for Youth
with Disabilities

GUIDE TO ABBREVIATIONS

UI = Unique identifier assigned to each reference.
AU = Up to three authors (last name and initials) are listed for journal articles, book chapters, or unedited books. If more than three individuals authored a document, "et al." appears after the first three names.
ED = Up to three editors (last name and initials) are listed for edited books or special journal issues. If more than three individuals edited a document, "et al." appears after the first three names.
BK = *Title of book.*
TI = *Name of journal article or book chapter.*
SO = Source: Journal title abbreviation or publisher of book, place of publication for books, date of publication, volume and issue number for journals, and pages.
KW = Keywords. Descriptive keywords list the primary intended audience(s) and the type(s) of document. Documents which report empirical research often have other information displayed describing the methodology. Topical keywords describe the type of illness or disability that is addressed as well as other topical descriptors.
AB = Abstract or significant findings.

A. BIBLIOGRAPHIC MATERIALS

1. General Medical and Social Aspects—Books

UI-10412 - Bibliographic Citation
BK- Chronic Disorders in Adolescence.
ED- Smith MS;
SO- John Wright-PSG: Boston, 1983:426;
KW- (descriptive); Primary intended audience: Health practitioners; Mental health, Social workers; Trainees; Educators, rehabilitation; Type of document: Review, general;
KW- (topical); Neoplasms (Cancer); Cystic fibrosis; Diabetes mellitus; Eating disorders; Mental, emotional disorders; Epilepsy, seizure disorders; Asthma; Congential heart defect; Hypertension; Inflammatory bowel disease, Crohn's; Juvenile rheumatoid arthritis; Chronic illness, general; Other chronic, disabling conditions; Death, dying; Individual stress, coping, social supports; Peer relations, communication; Developmental processes; Family; Special education; Vocational education; School adjustment, achievement; Individual assessment, diagnosis; Treatment, intervention;
AB- Smith and numerous colleagues, most from the University of Washington in Seattle, explore the spectrum of chronic disorders in adolescence with guidelines for the clinician who will provide general, continuous health care to patients with a variety of disorders, rather than highly specialized care to one subset of chronically ill youth. The text begins with reviews of physical and psychological development, the general effects of chronic illness on self, family, peer relations, and school, special educational and vocational considerations, the response to hospitalization and role of the specialized adolescent unit, death and dying in adolescence, and stress management techniques applicable to any disorder.

UI-11748 - Bibliographic Citation
BK- Chronic Illness and Disabilities in Childhood and Adolescence.
ED- Blum RW;
SO- Grune and Stratton: NY,1984:474;
KW- (descriptive); Primary intended audience: Health practitioners; Mental health, social workers; Trainees; Educators, Rehabilitation; Type of document: Review, general; Empirical Research;
KW- (topical); Chronic illness, general; Cystic fibrosis; Diabetes mellitus; Epilepsy, seizure disorders; Sickle cell anemia; Cancer; Renal disease; Psychosocial; Family; Sexuality; Economic issues; Policy issues; Role of government; Administration;
AB- This edited volume stresses the psychosocial implications of chronic illness for adolescents. Most chapters discuss a single illness while others address issues common to adolescents across illness categories.

UI-11471 - Bibliographic Citation
AU- Batshaw ML; Perret YM;
BK- Children with Handicaps - A Medical Primer.
SO- Paul H. Brookes: Baltimore, 1986:473;
KW- (descriptive); Primary intended audience: Mental health, social workers; Trainees; Educators, rehabilitation; Type of document: Review, general; Descriptive, case studies;
KW- (topical); Phenylketonuria; Attention-deficit disorders, hyperactivity; Learning disabilites; Schizophrenia, psychosis, autism; Epilepsy, seizure disorders; Hearing impairment; Vision impairment; Genetic conditions; Mental retardation (incl. Downs); Family; Contraception; Education; Policy, planning, and legal rights issues;
AB- Written in language appropriate for educators, this comprehensive text regarding medical aspects of children and youth with handicapping conditions provides in-depth studies of particular conditions. More than 130 detailed illustrations and a glossary are included.

UI-11827 - Bibliographic Citation
AU- Hobbs N; Perrin JM; Ireys HT;
BK- Chronically Ill Children and their Families.
SO- Jossey-Bass: San Francisco,1985:406;
KW- (descriptive); Primary intended audience: Health practitioners; Mental health, social workers; Trainees; Researchers; Educators, rehabilitation; Type of document: Review, general;
KW- (topical); Chronic Illness, General; Individual stress, coping, social supports; Family stress, coping, social supports; Family relationships, communication; Socioeconomic status, financial resources; Education; Employment and Vocational Rehabilitation; Ethics; Preservice training, education; Continuing training, education; Economic issues; Planning issues; Policy issues; Research;
AB- Discussion of the epidemiology of chronic illnesses; their effects on children, families and communities; health, education, employment and social service needs; financing of care; professional development; directions for future research; professional ethics; and policy options.

UI-11837 - Bibliographic Citation
BK- Issues in the Care of Children with Chronic Illness.
ED- Hobbs N; Perrin JM;
SO- Jossey-Bass: San Francisco,1985:953;
KW- (descriptive); Primary intended audience: Health practitioners; Mental health, social workers; Trainees; Researchers; Educators, rehabilitation; Type of document: Review, general;
KW- (topical); Neoplasms (cancer); Cystic fibrosis; Diabetes mellitus; Sickle cell anemia; Hemophilia; Spina bifida, myelodysplasia, meningomyelocele; Asthma; Congential heart defect; Musculoskeletal, connective system diseases; Facial anomalies; Chronic illness, general; Renal disease; Individual issues; Family stress, coping, social supports; Education; Employment and vocational rehabilitation; Teaming; Etiology, clinical features; Preservice training, education; Continuing training, education; Advocacy issues; Economic issues; Planning issues;Policy issues;
AB- A major text in the field including discussions of basic concepts of chronic illness; epidemiology, demography, and representative conditions; populations with special needs; provision of services and professional training; educational and vocational issues; programs and organizations serving chronically ill children and their families; and economic considerations. 42 chapters.

UI-12017 - Bibliographic Citation
BK- Understanding the Child with a Chronic Illness in the Classroom.
ED- Fithian J;
SO- Oryx: Phoenix, AZ,1984:245;
KW- (descriptive); Primary intended audience: Educators, rehabilitation; Type of document: Review, general;
KW- (topical); Neoplasms (cancer); Cystic fibrosis; Diabetes mellitus; Sickle cell anemia; Hemophilia; Epilepsy, seizure disorders; Asthma; Congential heart defect; Rheumatic heart disease; Musculoskeletal, connective system diseases; Juvenile rheumatoid arthritis; Muscular dystrophy; Mental Retardation (incl. Downs); School adjustment, achievement; Etiology, clinical features;
AB- Intended for teachers with little background in health, this book describes 13 chronic illnesses and their impact on children in school.

UI-12330 - Bibliographic Citation
AU- Wallace HM; Biehl RF; Oglesby AC; et al.;
BK- Handicapped Children and Youth. A Comprehensive Community and Clinical Approach.
SO- Human Sciences Press: New York,1987:378;
KW- (descriptive); Primary intended audience: Health practitioners; Mental health, social workers; Trainees; Educators, rehabilitation; Type of document: Review, general;
KW- (topical); Handicaps/DD, general; Sexuality; Daily living skills; Personal services, home health aides; Treatment, intervention; Program development; Evaluation; Case management; Advocacy issues; Civil liberties, rights issues; Planning issues; Role of government;
AB- Professionals from many disciplines contributed to this text designed for a broad audience of professionals. The first chapters describe definitions of disability, the impact on children and families, historical approaches to services, and current services within public programs and voluntary organizations. Subsequent chapters address legal rights, advocacy, early identification and screening, evaluation and management, nutritional needs, oral health, the role of various professionals, special education, sexuality, respite care, transportation, and state and community programs. The last third of the book includes overviews of many handicapping conditions. This could be a useful introductory text for students in many disciplines who will deal with children with disabilities.

UI-12337 - Bibliographic Citation
BK- Medical Problems in the Classroom: The Teacher's Role in Diagnosis and Management (2nd Edition).
ED- Haslam RHA; Valletutti PJ;
SO- Pro-Ed:Austin, TX,1985:481;
KW- (descriptive); Primary intended audience: Educators, rehabilitation; Type of document: Review, general;
KW- (topical); Endocrine, nutritional, metabolic; Growth delay; Mental, emotional disorders; Attention-deficit disorders, hyperactivity; Cerebral palsy; Hearing impairment; Vision impairment; Genetic conditions; Chronic illness, general; Mental retardation (incl. Downs); Behavior problems; Physical (puberty) development; Sexuality; Regular education; Recreation, leisure, sports, arts; Individual assessment, diagnosis; Case management; Teaming;
AB- Excellent textbook designed to help educational personnel understand and adapt to a broad spectrum of childhood health problems. The material is well-organized, well illustrated, and quite readable. Initial chapters review the role of teachers in early diagnosis and referral in prevention of disabilities. Chapters are devoted to normal growth and development and various disabilities.

UI-10435 - Bibliographic Citation
AU- Gliedman J; Roth W;
BK- The Unexpected Minority: Handicapped Children in America.
SO- Harcourt, Brace, Jovanovich: NY, 1980
KW- (descriptive); Primary intended audience: Health practitioners; Mental health, Social workers; Trainees; Researchers; Educators, rehabilitation, family, youth, general; Type of document: Review, general;
KW- (topical); Handicaps/DD, general; Chronic illness, general; Psychosocial Issues; Family; Education; Employment and vocational rehabilitation; Community and independent living; Advocacy issues; Civil liberties, rights issues; Deinstitutionalization issues; Economic issues; Cost, benefit analysis issues; Epidemiology; Legislation, litigation issues; Interagency collaboration issues; Media issues; Planning issues; Policy issues; Role of government;

2. Demographic

UI-11338 - Bibliographic Citation
AU- Gortmaker SL; Sappenfield W;
TI- Chronic childhood disorders: Prevalence and impact.
SO- Pediatr Clin North Am 1984 Feb;31(1):3-18;
KW- (descriptive); Primary intended audience: Health practitioners; Type of document: Review, general;
KW- (topical); Neoplasms (cancer); Cystic fibrosis; Diabetes mellitus; Phenylketonuria; Sickle cell anemia; Hemophilia; Mental, emotional disorders; Cerebral palsy; Epilepsy, seizure disorders; Hearing impairment; Spina bifida, myelodysplasia, meningomyelocele; Vision impairment; Asthma; Congential heart defect; Juvenile rheumatoid arthritis; Muscular dystrophy; Head trauma; Spinal cord trauma; Chronic illness, general; Mental retardation (incl. Downs); Etiology, clinical features; Epidemiology;
AB- Review of a wide range of chronic illnesses with an emphasis on areas of change and their implications.

UI-11824 - Bibliographic Citation
AU- Newacheck PW; Budetti PP; Halfon N;
TI- Trends in activity-limiting chronic conditions among children.
SO- Am J Public Health 1986 Feb;76(2):178-84;
KW- (descriptive); Primary intended audience: Health practitioners; Researchers; Type of document: Empirical research;
KW- (topical); Chronic illness, general; Attitudes toward people with disabilities; Epidemiology;
AB- Analysis of data from the National Health Interview Survey indicating an increase of prevalence of activity-limiting chronic conditions among children under 17 years from 1.8% in 1960 to 3.8% in 1981, with approximately 40% of the increase occurring before 1970. After 1970, the increase in prevalence was due to increases in the less-severe forms of limitations.

UI-11839 - Bibliographic Citation
AU- Garell DC;
TI- Beyond survival of the fittest: Adolescents with chronic illness in the year 2000.
BK- Proceedings of the Health Futures of Adolescents Conference.
SO- Society for Adolescent Medicine; Adolescent Health Program, U of MN:Adolescent Health Program, NCYD, Box 721 UMHC, Harvard at E. River Road, University of Minnesota, Mpls., MN 55455, 1986 .
KW- (descriptive); Primary intended audience: Health practitioners; Mental health, social workers; Trainees; Type of document: Review, general;
KW- (topical); Chronic illness, general; Family stress, coping, social supports; Competitive employment; Job development; Planning issues;
AB- Discussion of epidemiologic and service delivery issues that affect planning including technology, in-home services, mainstreaming, support systems, long-term planning, parental involvement, self-help efforts, and changes in the marketplace.

3. School Issues

UI-10783 - Bibliographic Citation
AU- Weitzman M; Walker DK; Gortmaker S;
TI- Chronic illness, psychosocial problems, and school absences.
SO- Clin Pediatr 1986 Mar;25(3):137-41;
KW- (descriptive); Primary intended audience: Mental health, social workers; Type of document: Empirical research; Type of research: Comparison/control group used; Randomly selected; Methodology: Interview with family member; Study size: 573; Sample age range: 6-17;
KW- (topical); Chronic illness, general; Individual issues; Social issues; School adjustment, achievement;
AB- In this study, children with chronic illness were found to miss more school than children without chronic illness. This difference was substantial among those with asthma, permanent stiffness, mental retardation, arthritis, seizures and cerebral palsy. Even children without functional impairments missed significantly more school than controls. Psychosocial problems were also associated with more missed school days, especially problems associated with learning and school, particularly when combined with a chronic illness. Poverty was also strongly associated with missing school.

UI-11074 - Bibliographic Citation
AU- Fowler MG; Johnson MP; Atkinson SS;
TI- School achievement and absence in children with chronic health conditions.
SO- J Pediatr 1985 Apr;106(4):683-7;
KW- (descriptive); Primary intended audience: Health practitioners; Mental health, social workers; Educators, rehabilitation; Type of document: Empirical research; Type of research: Comparison/control group used; Sample Description: Clinics/hospitals; Methodology: Interview with family member; Interview with professional; Records' review; Study size: 270; Sample mean age: 12;
KW- (topical); Chronic illness, general; School adjustment, achievement;
AB- Data was collected for children and adolescents with the following conditions: arthritis, blood disorder, cardiac disease, chronic bowel disease, chronic lung disease, cystic fibrosis, diabetes, epilepsy, hemophilia, sickle cell disease, and spina bifida. Achievement scores were lower and numbers of days absent were higher for children with chronic illnesses. Achievement scores did not correlate with number of days absent, but rather with socioeconomic factors and specific health condition (spina bifida, sickle cell disease, and epilepsy).

UI-11336 - Bibliographic Citation
AU- Walker DK;
TI- Care of chronically ill children in schools.
SO- Pediatr Clin North Am 1984 Feb;31(1):221-33;
KW- (descriptive); Primary intended audience: Health practitioners; Educators, rehabilitation; Type of document: review, general;
KW- (topical); Chronic illness, general; Education; Special education; School adjustment, achievement; Least restrictive environment; Individual education plan; Teaming;
AB- Discussion of educational placement, school services, and the pediatrician's role in the schools. In view of regulations requiring that schools accommodate children with a wide variety of chronic illnesses, this article identifies the major issues that must be addressed by schools and proposes guidelines for appropriate school care. Services required are described: support therapies (speech/language, occupational, and physical); schedule modifications; modified physical education; transportation; building accessibility; toileting/lifting assistance; counseling services (school, career, and personal); and school health services (administration of medications, implementation of medical procedures, emergency preparations, case coordination).

UI-12659 - Bibliographic Citation
AU- Chekryn J; Deegan M; Reid J;
TI- Normalizing the return to school of the child with cancer.
SO- J Assoc Pediatr Oncol Nurses 1986 ;3(2):20-4,34;
KW- (descriptive); Primary intended audience: Health practitioners; Mental health, social workers; Educators, rehabilitation; Type of document: Descriptive, case studies;
KW- (topical); Neoplasms (cancer); Individual issues; Individual stress, coping, social supports; Social issues; Peer relations, communication; Family; Regular education; School adjustment, achievement; Parent, family involvement; Service delivery; Treatment, intervention; Confidentiality, communication;
AB- This article draws upon information derived from interviews with parents, teachers, and 10- to 16-year-old children with cancer. All perceived school as a normalizing influence, while describing the difficulties of reentry. Ways in which health professionals and teachers can foster positive reentry are discussed. Strategies are sugested which can help children keep up academically when unable to attend classes.

4. Psychosocial and Family Issues

UI-10817 - Bibliographic Citation
AU- Beck AL; Nethercut GE; Crittenden MR; et al.;
TI- Visibility of handicap, self-concept, and social maturity among young adult survivors of end-stage renal disease.
SO- J Dev Behav Pediatr 1986 Apr;7(2):93-6;
KW- (descriptive); Primary intended audience: Health practitioners; Mental health, social workers; Type of document: Empirical research; Methodology: Interview with youth; Study size: 31; Sample age range: 18-29;
KW- (topical); Renal Disease; Individual issues; Body image, self-concept; Social, psychological development;
AB- This study found visibility of handicap to be inversely related to identity stability, social maturity, and self-esteem. All patients had undergone transplant surgery at least once, but seven remained on dialysis. The researchers also suggest that time may contribute to improved adjustment due to the finding of a positive correlation between self esteem and years since last transplant.

UI-11188 - Bibliographic Citation
AU- Orr DP; Weller SC; Satterwhite B; et al.;
TI- Psychosocial implications of chronic illness in adolescence.
SO- J Pediatr 1984 Jan;104(1):152-7;
KW- (descriptive); Primary intended audience: Health practitioners; Mental health, social workers; Type of document: Empirical research; Type of research: Longitudinal; Comparison/control group used; Methodology: Interview with youth; Youth questionnaire/self report; Study size: 144; Sample age range: 13-22;
KW- (topical); Chronic illness, general; Psychosocial issues;
AB- This is an eight-year follow-up of children with a chronic illness. Health status at follow-up correlated with eight psychosocial variables: planning for the future, engaging in family activities, dating, possession of a driver's license, talking with parents, satisfaction with family life, school enrollment and school adjustment. While most of the adolescents with chronic illness showed normal adjustment, those who experienced a resulting impairment were most at risk for problems in the above areas.

UI-11441 - Bibliographic Citation
AU- Morgan SA; Jackson J;
TI- Psychological and social concomitants of sickle cell anemia in adolescents.
SO- J Pediatr Psychol 1986 Sep;11(3):429-40;
KW- (descriptive); Primary intended audience: Health practitioners; Mental health, social workers; Type of document: Empirical research; Type of research: Comparison/control group used; Sample description: Black; Methodology: Youth questionnaire/self report; Study size: 48;
KW- (topical); Sickle cell anemia; Body image, self-concept; Individual stress, coping, social supports; Social issues; Etiology, clinical features;
AB- Study of 24 patients compared with 24 healthy adolescents supporting the hypothesis that affected adolescents are at an increased risk for adjustment problems. This study examined measures of: body satisfaction, depression, and social withdrawal. In all three areas, adolescents with sickle cell anemia were found less well adjusted than matched controls. The authors assert that, to some extent, these findings may reflect a realistic response to life circumstances. Studies of adolescents with similar types of illness have yielded similar findings. The authors suggest disease-related variables (growth retardation, delayed puberty, limited physical capacity, and academic underachievement) may underlie their findings.

UI-11677 - Bibliographic Citation
AU- Smith MS; Gad MT; O'Grady L;
TI- Psychosocial functioning, life change, and clinical status in adolescents with cystic fibrosis.
SO- J Adol Health Care 1983 Dec;4(4):230-4;
KW- (descriptive); Primary intended audience: Health practitioners; Mental health, social workers; Type of document: Empirical research; Type of research: Cross-sectional; Sample description: Clinics/hospitals; Methodology: Laboratory/psychometric tests; Physical examination; Youth questionnaire/self report; Study size: 26; Sample age range: 12-18;
KW- (topical); Cystic fibrosis; Body image, self-concept; Locus of control, independence; Individual stress, coping, social supports; School adjustment, achievement;
AB- Results indicate generally favorable adjustment and self-esteem of adolescents with cystic fibrosis, with the majority at grade level, participating in physical education classes, and planning for college and/or career. These adolescents reported a relatively external locus of control and adequate social support from friends and family. Overall, a measure of life event changes found these adolescents to be comparable to the norm, but higher scores were found for those adolescents with a higher level of health impairment.

UI-11686 - Bibliographic Citation
AU- Smith G;
TI- A patient's view of cystic fibrosis.
SO- J Adol Health Care 1986 Mar;7(2):134-8;
KW- (descriptive); Primary intended audience: Health practitioners; Mental health, social workers; Trainees; Educators, rehabilitation; Family, youth, general; Type of document: Commentary/editorial;
KW- (topical); Cystic fibrosis; Attitudes toward people with disabilities; Death, dying; Body image, self-concept; Individual stress, coping, social supports; Peer relations, communication; Quality of life; Family relationships, communication;
AB- An eloquent and thought-provoking account of a young man's experience of life with cystic fibrosis.

UI-11743 - Bibliographic Citation
AU- Zeltzer L; Kellerman J; Ellenberg L; et al.;
TI- Psychologic effects of illness in adolescence. II. Impact of illness in adolescents - Crucial issues and coping styles.
SO- J Pediatr 1980 Jul;97(1):132-8;
KW- (descriptive); Primary intended audience: Health practitioners; Mental health, social workers; Type of document: Empirical research; Type of research: Comparison/control group used; Sample description: Schools; Clinics/hospitals; Methodology: Youth questionnaire/self report; Study size: 513;
KW- (topical); Neoplasms (cancer); Cystic fibrosis; Diabetes mellitus; Circulatory, respiratory system diseases; Juvenile rheumatoid arthritis; Renal Disease; Locus of control, independence; Peer relations, communication; Social, psychological development; Family relationships, communication; Sexual development, psychosocial; School adjustment, achievement;
AB- Comparison of 345 healthy and 168 adolescents with chronic illnesses. The psychologic normalcy found indicates a need for psychosocial rather than intrapsychic rehabilitation. Adolescents with a major chronic illness did not differ from healthy peers in the total perceived impact of illness on their lives. Adolescents perceived the areas of illness impact differently according to the type of illness they had. Females were more concerned with physical appearance than males were.

UI-11818 - Bibliographic Citation
AU- Woodhead JC; Murph JR;
TI- Influence of chronic illness and disability on adolescent sexual development.
SO- Semin Adol Med 1985 Sep;1(3):171-6;
KW- (descriptive); Primary intended audience: Health practitioners; Mental health, social workers; Trainees; Educators, rehabilitation; Type of document: Review, general;
KW- (topical); Chronic illness, general; Developmental processes; Sexual development, psychosocial;
AB- Discussion of sexual issues with a psychosocial emphasis as relating to chronic illness and disability by developmental level.

UI-12097 - Bibliographic Citation
AU- Margalit M; Cassel-Seidenman R;
TI- Life satisfaction and sense of coherence among young adults with cerebral palsy.
SO- Career Dev Excep Indiv 1987 Spring;10(1):42-50;
KW- (descriptive); Primary intended audience: Educators, rehabilitation; Type of document: Empirical research; Type of research: Cross-sectional; Methodology: Interview with youth; Study size: 34; Sample mean age: 24.4;
KW- (topical); Cerebral palsy; Locus of control, independence; Individual stress, coping, social supports; Quality of life;
AB- Results indicate limited life options for these young adults who, nonetheless, report relatively high life satisfaction. Regression analysis found that 1) a feeling of meaningfulness, 2) the amount of support and guidance received, and 3) feelings of manageability and control accounted for 66% of the variance in life satisfaction.

UI-12193 - Bibliographic Citation
AU- Sinnema G; Bonarius HC; VanderLaag H; et al.;
TI- The development of independence in adolescents with cystic fibrosis.
SO- J Adol Health Care 1988 Jan;9(1):61-66;
KW- (descriptive); Primary intended audience: Health practitioners; Mental health, social workers; Type of document: Empirical research; Type of research: Comparison/control group used; Sample description: Clinics/hospitals; Caucasian; Methodology: Interview with youth; Study size: 218; Sample age range: 12-20;
KW- (topical); Cystic fibrosis; Growth delay; Asthma; Locus of control, independence; Individual stress, coping, social supports; Peer relations, communication; Physical (puberty) development; Family structure, process; Sexual development, psychosocial;
AB- Compared to adolescents who had asthma or who had short stature or who were normal, healthy controls, adolescents with cystic fibrosis were found to show less responsibility for their own body hygiene, to have a delay in intimacy and sexuality, and to take less part in social activities outside the home. There were minimal or no differences between ill and healthy adolescents for four elements. The correspondence between the chronically ill and the healthy adolescents prevailed over the differences. The main differences could be interpreted in terms of realistic coping with the illness and maintaining hope for the future.

UI-12458 - Bibliographic Citation
AU- Gunther MS;
TI- Acute-onset serious chronic organic illness in adolescence: Some critical issues.
SO- Adolesc Psychiatry 1985 ;12:59-76;
KW- (descriptive); Primary intended audience: Health practitioners; Mental health, social workers; Trainees; Type of document: Review, general;
KW- (topical); Chronic illness, general; Individual issues; Individual stress, coping, social supports; Developmental processes; Social, psychological development; Needs assessment;
AB- Discussed psychological impact of serious, chronic organic disease. Enumerates common reactions to serious illnesses (acute or chronic): affect (anxiety, guilt, surprise, resentment, depression); fear (of separation, of the unknown, of pain, of treatment, of the future); regression; introversion; attitudes toward health professionals (dependence, idealization, angry disappointment, resentment); aggression; defensiveness. Describes specific adolescent adaptations of these reactions. Discusses normative development as it relates to chronic illness. Concludes with suggestions of factors which practitioners can influence.

B. Training Materials

UI = Unique identifier assigned to each reference.
MT = Material title.
SP = Supplier.
AD = Address.
PH = Phone number.
PR = Producer and date.
KW = Keywords. Descriptive keywords list type of medium, training mode, primary intended audience, general focus, and price. Topical keywords describe the type of illness or disability that is addressed as well as other topical descriptors.
AB = Abstract, narrative description.

UI-10099 - Training
MT- School: Obstacle or Opportunity? - Coping with Chronic Illness in the Secondary Classroom
SP- Pam Mattson
AD- Hematology/Oncology Division, Children's Hospital Medical Center, Elland and Bethesda Avenues, Cincinnati,OH 45229
PH- (513) 559-4266
PR- Lynette Miller; 1984
KW- (descriptive); Type of medium; Videotape: 25 minutes; 1/2 inch VHS;3/4 inch U-Matic; Training mode: General presentation of issues; Primary intended audience: Professionals (preservice or continuing education); Youth, families, and general public; General focus: Health; Education or rehabilitation; Rental: $50/week; Purchase: $200;
KW- (topical); Handicaps/DD, general; Neoplasms (cancer); Epilepsy, seizure disorders; Juvenile rheumatoid arthritis; Chronic illness, general; Attitudes toward people with disabilities; Death, dying; Individual issues; Social issues; Social, psychological development; Family; Education; Professional issues;
AB- "School: Obstacle or Oportunity" is aimed at helping secondary school staffs cope with chronic illness in the classroom. Interviews are done with principals and educators themselves who have dealt with chronic illness effectively on a secondary level. Practical tips are offered to school staffs in dealing with teenagers with cancer, epilepsy, juvenile arthritis, and other chronic illnesses. Cancer is used as a model for how students and teachers cope in the classroom, but the fact that the issues are the same for teenagers with other chronic illnesses is strongly emphasized. Audiovisual program won awards from the American Cancer Society and the Association for the Care of Children's Health.

UI-10098 - Training
MT- Practically Speaking
SP- Pam Mattson, Education Assistant
AD- Hematology/Oncology Division, Children's Hospital Medical Center, Elland & Bethesda Avenues, Cincinnati,OH 45229
PH- (513) 559-4266
PR- Lynette Miller; 1988
KW- (descriptive); Type of medium; Pamphlet/booklet; Training mode: General presentation of issues; Primary intended audience: Professionals (preservice or continuing education); General focus: Health; Education or rehabilitation; Purchase: Free;
KW- (topical); Neoplasms (cancer); Chronic illness, general; Attitudes toward people with disabilities; Death, dying; Individual issues; Social issues; Regular education; Health education, school health; Parent, family involvement; Confidentiality, communication; Preservice training, education; Continuing training, education;
AB- "Practically Speaking" is a small booklet aimed at helping school staffs feel more comfortable in the classroom in dealing with chronic illness. Practical pointers are offered as a way of acknowledging that teachers often have many tasks to juggle in the classroom, and so this booklet helps to make confronting chronic illness less threatening and overwhelming.

UI-10137 - Training
MT- Coping With Cancer: The Middle School Years
SP- American Journal of Nursing Co.
AD- 555 West 57th Street, New York, NY 10019
PH- (212) 582-8820
PR- Memorial Sloan-Kettering Cancer Center ;1983
KW- (descriptive); Type of medium; Videotape: 36 minutes; 1/2 inch VHS; 3/4 inch U-Matic; Training mode: General presentation of issues; Primary intended audience: Professionals (pre-service or continuing education); Youth, families, and general public; General focus: Health; Mental health or social work; Education or rehabilitation; Price; Rental: $60.00; Purchase: $200.00; KW- (topical); Neoplasms (cancer); Death, dying; Individual issues; Individual stress, coping, social supports; Social issues; Family stress, coping, social supports; Community and independent living;
AB- Because children aged 12-14 gain so much of their support from peers, this program opens the door on three young patients in a therapeutic group setting. Here the viewer gains vital insights difficult to acquire in any other way: how these children felt when their cancer was diagnosed; when they returned to school; when peers asked qestions; when fellows in the hospital died; when their treatments caused pain, hair loss and fear; when they were teased or friends failed to understand.

UI-10135 - Training
MT- Coping With Cancer: The High School Years
SP- American Journal of Nursing Co.
AD- 555 West 57th Street, New York, NY 10019
PH- (212) 582-8820
PR- Memorial Sloan-Kettering Cancer Center; 1983
KW- (descriptive); Type of medium; Videotape: 37 minutes; 1/2 inch VHS; 3/4 inch U-Matic; Training mode: General presentation of issues; Primary intended audience: Professionals (pre-service or continuing education); Youth, families, and general public; General focus: Health; Mental health or social work; Education or rehabilitation; Price; Rental: $60.00; Purchase: $200.00; KW- (topical); Neoplasms (cancer); Psychosocial issues; Death, dying; Peer relations, communication; Quality of life; Family stress, coping, social supports; Individual education plan; Daily living skills; Health concerns; Treatment, intervention;
AB- At a difficult age, with a complicated disease, six courageous teenage patients shed light on the range of their emotions as they encounter their peers, teachers and parents; as they fight to maintain and increase their independence, a struggle made more difficult by overly protective, worried adults; and as they discover one of life's miracles - that their fight with cancer has strengthened and enriched them.

UI-10138 - Training
MT- Don't Freeze Me Out
SP- Landmark Films
AD- 3450 Slade Run Dr., Falls Church, VA 22042
PH- (800) 342-4336
PR- Pat Mochel; 1987
KW- (descriptive); Type of medium; Videotape: 16 minutes; 1/2 inch VHS; 3/4 inch U-Matic; Training mode: General presentation of issues; Primary intended audience:professionals (pre-service or continuing education); Youth, families, and general public; General focus: Mental health or social work; Education or rehabilitation;
KW- (topical); Neoplasms (cancer); Attitudes toward people with disabilities; Body image, self-concept; Individual stress, coping, social supports; Peer relations, communication; Discrimination; School adjustment, achievement; Continuing education; Continuing training, education;
AB- Don't Freeze Me Out features members of the Adolescent Oncology Support Group at Johns Hopkins Hospital in Baltimore, MD. The tape explores their feelings and experiences on returning to school after chemotherapy, bone marrow transplants, surgery, or other treatments for cancer. The message of the tape is targeted at fellow students, teachers, and administrators who are ignorant or callous toward their fragile state after the treatment. The tape is part documentary/part music video, with an original song, to appeal to teenagers.

C. Program Descriptions

NM = Name of the program.
CT = Contact person(s).
AF = Affiliation.
AD = Address.
PH = Phone number.
KW = Keywords. Descriptive keywords describe the scope of the program, the population served, the types of services provided, the times of year the program is operational, the focus of the program, and whether or not it publishes a newsletter regarding youth with disabilities. Topical keywords describe the chronic illnesses or disabilities that are addressed.
AB = Narrative abstract of program.

UI-10007 - Programs/Projects
NM- Comprehensive Pediatric Rheumatology Center, Prevocational Training Program for Adolescents with Rheumatic Diseases and Other Chronic Illnesses
CT- White Patience, Dr. & Gaumond Margaret, MSW
AF- Children's Hospital National Medical Center
AD- 111 Michigan Avenue, N.W. Washington,D.C. 20010
PH- (202) 745-3203
KW- (descriptive); Scope of program: Multi-state regional: DC, MD, VA, WV; Population served: Urban; Suburban; Small cities/communities; Rural; Types of services provided: Direct service; Information and referral; Consultation; Teaching; Research; No fee for I & R; Does not charge a fee for consultative services; Operational entire year (12 months); Description of focus of program: Hospital-based specialty care; Education; Vocational and career services; Advocacy; Interagency collaboration; Psychosocial issues; Other: Area-wide outreach; Does not publish newsletter re: youth with disabilities;
KW- (topical); All chronic illness or disability;
AB- The goal of the Comprehensive Pediatric Rheumatology Center's Prevocational Training Program is to improve vocational readiness in adolescents, ages 12-19, with chronic illnesses. The program includes the components of SERVICE including assessment, job placement and the development of a vocational resource directory; EDUCATION including prevocational conferences for adolescents and their families, educational advocacy, courses, and the Next-Steps Planning for Employment course; EVALUATION/RESEARCH including the expansion of computerized data-base to include vocational maturity and job experience variables. Pre and post-evaluation of program.

UI-10234 - Programs/Projects
NM- The Adolescent Day Hospital of Chronically Ill Adolescents/The First State School
CT- Kramer Janet P., MD, Director of Adolescent Med.
AF- Medical Center of Delaware
AD- Christiana Hospital, P.O. Box 6001, 4C-4107, Newark, DE 19718
PH- (302) 733-4107
KW- (descriptive); Scope of program: Local: New Castle County, Delaware; Population served: Urban; Suburban; Small cities/communities; Types of services provided: Direct service; Consultation; Teaching; Research; Does charge a fee for consultative services; Fees for consultative services are negotiable; Operational entire year (12 months); Description of focus of program: Primary health care or hospitalization; Hospital-based specialty care; Physical medicine and rehabilitation; Education; Vocational and career services; Social services; Sexuality; Advocacy; Interagency collaboration; Psychosocial issues; Developmental processes; Family; Other;
KW- (topical); Neoplasms (cancer); Endocrine, nutritional, metabolic; Blood, immune system diseases; Other mental, emotional disorders; Central nerve system, sense organ diseases; Circulatory, respiratory system diseases; Digestive system diseases; Musculoskeletal, connective system diseases; Muscular dystrophy; Neurofibromatosis; Chronic pain; Chronic illness, general; Renal disease; Mental retardation (incl. Downs);
AB- The Adolescent Day Hospital for Chronically Ill Adolescents, a first of its kind in the U.S., is an educational-medical program co-sponsored by the Medical Center of Delaware and the Delaware Department of Instruction to promote intellectual, social, emotional growth for homebound adolescents in sixth through 12th grade who are too ill to attend regular school. On school days year round, the adolescents are transported to and from the Medical Center and home on special buses and receive their medical care, i.e., renal dialysis, IV's, chemotherapy, physical therapy, etc., while attending an educationally excellent program which includes peer support, family support, psychological services, and career-transition planning.

UI-10231 - Programs/Projects
NM- Dialysis Unit for Pennsylvania State University Students
CT- McQueary John, Administrator
AD- 3901 S. Atherton Street, Suite 5, State College,PA 16801
PH- (814) 466-7911
KW- (descriptive); Scope of Program: National; Population served: Urban; Suburban; Small cities/communities; Rural; Types of services provided: Direct service; Research; Operational entire year (12 months); Description of focus of program: Primary health care or hospitalization; Education; Vocational and career services; Vocational rehabilitation; Independent living; Social services; Interagency collaboration; Does not publish newsletter re: youth with disabilities;
KW- (topical); Renal disease;
AB- This is the first facility anywhere to provide multi-level support to young people with kidney disease who want to pursue their education. The program helps them prepare for careers and develop independence in managing their daily lives and their illness. Housed in off-campus apartments, the unit offers special personnel and facilities. A resident counselor and an educational coordinator provide counseling and academic assistance. A dietician helps students plan meals that fit their renal diets. A physician and a head dialysis nurse oversee medical care. Construction of an on-site dialysis unit will begin soon. Students also benefit from enrolling in special courses at the Pennyslvania State University.

UI-10060 - Programs/Projects
NM- Diabetes Project Unit
CT- Silverstein Janet or Geffken Gary
AF- University of Florida
AD- University of Florida, Box J-296 JHMHC, Gainesville, FL 32610
PH- (904) 392-2708
KW- (descriptive); Scope of program: Statewide: FL; Population served: Urban; Suburban; Small cities/communities; Rural; Types of services provided: Direct service; Consultation; Teaching; Research; No fee for I & R; Does charge a fee for consultative services; Fees for consultative services are negotiable; Operational entire year (12 months); Description of focus of program: Primary health care or hospitalization; Mental health; Vocational and career services;Independent living; Psychosocial issues; Family; Does not publish newsletter re: youth with disabilities;
KW- (topical); Diabetes mellitus;
AB- This is a state funded residential center within the hospital of the University of Florida. This program was designed for youths unable to cope with diabetes, requiring frequent hospitalization, or with multiple school absences or school failure. The youth attend public school and live in a dorm-like setting. They are supervised by parent surrogates 24 hours a day. The youths, in addition to participating in public school activities, also have diabetes education sessions as well as twice weekly individual psychotherapy and weekly family counseling. Group therapy sessions take place once a week. Medical rounds formally take place once a week, but medical intervention is applied when indicated.

UI-10045 - Programs/Projects
NM- University of South Florida Diabetes Center-Children's Diabetes Program
CT- Malone John I., M.D.
AF- University of South Florida College of Medicine
AD- 12901 Bruce B. Downs Blvd., Box 45, Tampa, FL 33612
PH- (813) 974-4360
KW- (descriptive); Scope of program: Local: FL (18 counties); Population served: Urban; Suburban; Small cities/communities; Rural; Types of services provided: Direct service; Information and referral; Consultation; Teaching; Research; No fee for I & R; Does charge a fee for consultative services; Fees for consultative services are negotiable; Operational entire year (12 months); Description of focus of program: Primary health care or hospitalization; Nutrition;Education; Social services; Psychosocial issues; Does publish newsletter re: youth with disabilities;
KW- (topical); Endocrine, nutritional, metabolic; Diabetes mellitus; Phenylketonuria;
AB- The Center is a treatment and education facility which serves patientswith diabetes and other endocrine disorders. We provide model care and treatment with the emphasis on the "team approach." The team consists of our staff, the patient and his family. Education is provided in clinic and through special workshops geared to all ages. Workshops for parents are also provided. The adolescent workshops are geared to the problems that they face, including peer pressure, communication, drugs and substance abuse, and sexuality. In-depth education of the survival skills is provided for newly diagnosed patients and their families in our outpatient facility. This education can last 2-5 days. Nutrition workshops are also provided.

UI-10238 - Programs/Projects
NM- Adolescent Trauma Recovery Program
CT- Slater Elisa J., Ph.D.
AF- University of Maryland Hospital
AD- UMH, Department of Pediatrics, 22 S Greene Street, Baltimore, MD 21201
PH- (301) 328-4865
KW- (descriptive); Scope of program: Multi-state regional: MD, DE, VA; Population served: Urban; Suburban; Small cities/communities; Rural; Types of services provided: Direct service; Information and referral; Consultation; Teaching; Research; No fee for I & R; Does charge a fee for consultative services; Fees for consultative services are not negotiable; Operational entire year (12 months); Description of focus of program: Primary health care or hospitalization; Hospital-based specialty care; Physical medicine and rehabilitation; Independent living; Social services; Psychosocial issues; Developmental processes; Family; Does not publish newsletter re: youth with disabilities;
KW- (topical); Head trauma;
AB- The ATRP is an interdisciplinary program. Several professionals work together to offer comprehensive rehabilitative care for teens with head injury. Medical, psychological, and educational needs are assessed. Depending on the individual, the following services are available; Adolescent Medical Care, Psychology, Neuropsychology, Adolescent Social Work, Nutrition, Short-Term Inpatient Care, and Speech Therapy. Addressing the varied needs of injured teens through this comprehensive approach is the primary goal of ATRP. Further, ATRP serves as a liaison between family and the school to facilitate school re-entry. ATRP aims for the eventual reintegration of the teen into family, school, and community life.

CYDLINE Reviews

Please copy and share the contents of this publication. We ask that you credit the National Center for Youth with Disabilities at the University of Minnesota as the source of information.

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